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ABSTRACT

Several conventional approaches to conceptualization and the measurement of objectives in publicly funded, long-term home care for the non-institutionalized elderly are reviewed critically. The formulation of objectives which focus on immediate, desired consequences of services, and lend themselves to behavioral measurement, is proposed. The quality of circumstances measurement approach to non-institutional, long-term care is introduced with two objectives: to provide adequate solutions to problems of daily living; and to reduce unreasonable caregiving burdens experienced by involved informal supports. Instruments designed to measure the degree to which these objectives are attained are described. The use of these instruments in a large, federally funded study of the impact of home services on the functionally disabled elderly in New York City is reported. (Author/AG)

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MEASURING ATTAINMENT OF OBJECTIVES IN NON-INSTITUTIONAL LONG TERM CARE

by

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ABSTRACT

Several conventional approaches to conceptualization and measurement of objectives in publicly funded long term care for the non-institutionalized elderly are reviewed critically. A case is presented for a formulation of objectives which focuses on immediate desired consequences of services and which lends itself to behavioral measurement. An approach is introduced in which non-institutional long term care has two objectives: 1) to provide adequate solutions to problems of daily living and 2) to reduce unreasonable caregiving burdens experienced by involved informal supports. Instruments designed to measure the degree to which these objectives are attained are described. The use of these instruments in a large federally funded study of the impact of home services on the functionally disabled elderly in New York City is reported.

MEASURING ATTAINMENT OF OBJECTIVES IN NON-INSTITUTIONAL LONG TERM CARE

With the emergence of substantial entitlement programs to provide long term care to the elderly in home settings, it is important to articulate objectives which can be used to guide their administration. Two important and interrelated dimensions of the home care policy domain deserve careful attention:

1) What should be accomplished for the disabled elderly through publicly funded noninstitutional programs?

2) How can we determine the extent to which public objectives have been attained?

A framework is presented here designed to have broad utility in evaluating publicly funded home care programs for the elderly. The paper also reflects an effort to operationalize the approach in a study of the impact of Medicaid-financed home service programs in New York City. Through its Human Resources Administration, New York City operates home care programs on an ongoing basis which serve over 36,000 persons at a cost to the public of approximately $300 million annually. We are engaged in a study funded by the Health Care Financing Administration to determine the consequences of these programs for the at-risk functionally disabled population and family members who are involved in their care. The framework was the basis for the instruments used to measure impact. The study provides us with an opportunity both to refine the instruments and to use them to address substantive questions. Since data collection is nearly complete, it is possible to report

on our experience in administering the instruments. It is too early, however, to report on the data we have generated.

In the current climate of increased appreciation of the need for accountability in public services, clarity of purpose and definition will help home care to attract major financing. A concern with objectives for clients will help to counter cost concerns. It will provide a rationale for arguing that a weekly expenditure of $100 is not enough -- or for explaining that 20 hours a week of in-home help is needed; that in other cases 5 or 10 hours a week is enough.

Home services traditionally have been justified as potentially less expensive than institutional care. (See, for example, Morris, 1971, Brickner and Scharer, 1977 and G.A.O., 1977.) The premise for this rationale is that a justification has been established for institutional care. If noninstitutional care can be offered at less cost to a comparable population, it can come under the same umbrella. A rationale for noninstitutional care which is independent of the prevention of institutionalization, however, is preferable for the following reasons:

1) There are more direct ways to influence levels of institutionalization than prevention through home services. One option is simply to reduce the number of institutional beds which are authorized. A second alternative which also is already being tried is to introduce tighter pre-admission screening procedures. (See, for example, Eggert, Bowlyow, and Nichols, 1980.) In reality, the circumstances under which institutional long term care is appropriate have not been fully established (Foley, Menger, and Schneider, 1980). Accordingly, when cost control

is of paramount concern, it is possible to justify more selective practices in admitting persons to long term care institutions at public expense.

2) Even if the average cost of in-home services is below that of institutional care, the aggregate public cost of public programs which finance in-home services are likely to exceed those which exclusively finance institutional care. The research evidence suggests that for every elderly person in an institution there are probably two or three with similar conditions living outside of institutions (Baltay, 1977). When home services are made available, some of the pool which would not use institutional care, can be expected to make use of home services. The result is a larger number of persons making use of publicly funded services and larger aggregate expenditures.

3) Even if it is possible to establish a cut-off point at which individual conditions are serious enough to warrant institutional care at public expense, it is not necessarily the case that the same cut-off is appropriate for home service.

While home services should not be justified as an alternative to institutionalization, retention of some reference to institutional care is useful in establishing parameters for home services. The nature of the services which are provided in institutions is useful in considering the services which might be offered in home settings. Further, expenditures for institutional services are useful in establishing cost guidelines for home services.

At the same time, some caution in using institutional services as a frame of reference are in order. Although institutional programs are well established and well structured, a careful examination would reveal a good deal of ambiguity about what these programs should accomplish. A more precise formulation of objectives might lead to important modification in institutional services leading, in turn, to changes in costs.

Before proposing how the purposes of home care should be conceived, it is useful to articulate five more premises:

1) It is helpful to think of long term care as fundamentally social care. Long term care is concerned with the consequences of congenital conditions, accidents, illnesses, or certain physiological and psychological processes associated with aging. Long term care, however, is different from the health care which is addressed to prevention or treatment of illness or injury.

2) Other boundaries of long term care pose definitional problems. In principle, long term care should be separate from mechanisms which assure individuals with economic resources sufficient for their survival needs. In reality, long term care is sometimes asked, in part, to fill in for inadequacies in basic economic resources.

3) It is preferable in long term care as in other service arenas to find a rationale in the outcome domain rather than among input or process variables. Objectives should address the well-being of an at-risk population. Objectives should not be articulated in units of services activities or in terms of numbers of persons served.

4) A rationale for services should be found in results which can actually be demonstrated. In the human services, the logic of linking hypothesized immediate, intermediate, and ultimate effects of services is often tenuous. If only immediate effects can be reasonably proven, it is preferable to find a rationale which is based on those feasible, immediate objectives. Similarly, objectives should be formulated in concepts which readily lend themselves to measurement. Accordingly, an approach which is based on observable conditions and behavior is preferable to one based on attitudes.

5) In part, it must be understood that a basic purpose of long term care is to sustain life. Because there are so many ways in which people can be kept alive, a more sensitive formulation which reflects quality of life is needed (Bloom, 1975 and Callahan and Wallack, 1981).

I propose that publicly funded home services have announced objectives both for disabled individuals and family members involved in their care.

1) For disabled individuals the objective of home services is to assure adequate solutions to problems of daily living. Home services should be concerned with persons with self-care deficits. Their purpose is to fill in for what individuals cannot do for themselves.

2) For families the purpose of home services is to relieve unreasonable burdens associated with caregiving. The premise is that in some instances, for family members, participation in long term care may have negative consequences for the caregiver. Publicly funded home

services should provide relief to caregiving family members so that participation in care does not exceed a reasonable level (Frankfather, Smith, Caro, 1981).

If these objectives are broadly acceptable, they lead to further questions. How should the objectives be operationalized? What are the problems of daily living with which home services should be concerned? How should standards of adequacy be set? How should conditions among those in the at-risk population be monitored so that the performance of home services can be soundly evaluated?

A first task in establishing an evaluation framework for disabled persons is to settle on the daily living dimensions to be included. A central premise is that the approach should be explicitly socio-cultural. The daily living dimensions should reflect not only physiological conditions but life styles in the society in which home services are offered. The list of daily living dimensions should begin with survival needs such as shelter, food, clothing, personal security, basic personal hygiene, and access to medical care. The list should also include needs for activity and self-expression as defined in the culture. The following are dimensions which might be included: privacy, personal freedom (or minimization of environmental constraints), grooming, and opportunities for sensory stimulation which might be obtained by access to print media, electronic media, outings, or even by looking out a window. Finally, the list probably should include opportunities for social contact. It must be acknowledged that the activity of self-expression domain is even more culturally defined than the survival needs domain. It should also be noted that in the activity and self-expression

domain, expectations must be tempered by limitations which are imposed by physiological impairments. For those with visual or hearing impairments, for example, visual and auditory experiences are no longer relevant. For those who have lost consciousness, the activity and self-expression dimensions appear to be entirely irrelevant. In individual cases, it may be difficult to judge how expectations for activity and self-expression should be adjusted because of a particular set of impairments.

A subtle issue in formulating objectives and evaluating services arises from the fact that some people refuse services which are offered to them. If persons in the population of concern experience inadequate solutions to problems of daily living but have refused some of the services apparently available, what inferences can be drawn regarding service adequacy? Refusal of service requires analysis. It may simply reflect a preference for an atypical lifestyle or may reflect a flaw in services which are offered. At issue is the question whether the public obligation is to assure that the disabled actually experience what are judged to be adequate solutions to problems of daily living or is it enough that they have <u>opportunities</u> to experience adequate solutions. In New York City last winter, for example, the media called attention to the case of an elderly woman who lived in a cardboard carton and died of exposure. She had been encouraged to go to a public shelter, but had refused. Was it enough that she was offered shelter? Assuming that she had an informed basis for refusing public shelter, was her refusal reasonable in light of the quality of the city's shelter services? Alternately, should she have been judged mentally incompetent?

Should the city have been expected to intervene in spite of her objections to assure a more conventional solution to her shelter needs?

If the dimensions of daily living to be addressed by home care can be identified, it is pertinent to turn to the question of the kinds of solutions to problems of daily living which are actually experienced by individuals. Measurement of actual conditions is preferable to measurement of perceived conditions. At issue is the question of how we can measure what is happening to recipients of home services. The measurement of conditions in this population presents inherent problems because the population is geographically dispersed. In many cases, even telephone contact may not be feasible. A number of potential sources of information can be identified: 1) consumer initiated reports, 2) reports of service providers, and 3) independent surveys. The technical problems in obtaining valid, sensitive data on conditions among home service recipients at an affordable price are enormous. The least expensive approach is to rely on consumer initiated reports, presumably complaints. These reports might come either from the recipient of service or a relative or friend. Because of uncertainties in the conditions which lead consumers to make complaints and the vagaries in ways in which complaints are received and recorded, an evaluation researcher would be reluctant to accept consumer initiated reports as anything but the crudest indicator of actual conditions or trends.

In principle, service workers might be expected to record data on conditions. They could be trained to do so systematically. In practice, service workers are likely to resist such data collection responsibility

on the grounds that it is excessively burdensome. Further, their reporting might well be biased in that service providers have an interest in showing that they have produced favorable results for clients.

Independent surveys are most likely to yield valid data but are expensive. Even when resources are available to conduct surveys of recipients of home services, difficult measurement problems can be anticipated. One approach in conducting such surveys, of course, is to rely on the elderly functionally disabled as informants. The ability of persons in this population to answer complex questions, to give sustained attention through a long interview, and their willingness to report accurately on their circumstances can all be questioned. In some circumstances proxy respondents may be used, but they, in turn, may also be uncertain sources of data. Proxies may not be well enough informed to provide all of the data needed and may be unwilling to admit their ignorance or to report accurately on some matters. Direct observation, a third option, is likely to be useful only within distinct limits. Observers, for example, may not have access to all areas within a residence. Further, observers would have to be present round-the-clock to be able to document fully the experiences of the persons of concern. Clearly such intensive observation is not at all feasible. With the brief, occasional visits which might be within the realm of possibility, observers are at risk of being exposed to rather carefully staged performances in which they see those at risk in the most favorable possible light.

In some domains pertinent measurement technology exists, but may not be available. It is, for example, of concern that the elderly disabled live in

well-heated quarters in winter. The technology exists for continuous monitoring and recording of temperatures. The technology also exists for communicating data to a central point. Such technology, however, might be considered too expensive for evaluation or monitoring purposes in a publicly-funded home service program. Instead, we are likely to have to rely on a subjective report of the adequacy of the heat provided in a residence.

A major problem with an approach which emphasizes actual circumstances arises from the sheer number of conditions which might be measured. In the shelter dimension alone, it is possible to generate an exceedingly long list of physical features which contribute to overall quality. The need for economy in data collection dictates that evaluation researchers settle for a manageable set of indicators rather than exhaustive measures of housing quality. Beyond the general sampling problem involved in indicator selection, lie two special problems. First, in some dimensions like housing, certain conditions occur rarely, but when they do occur they make a dwelling unacceptable. A furnace combustion-ventilation problem which leads to seepage of carbon monoxide into living spaces is potentially fatal but rare. In the absence of extremely thorough measurement, problems of this nature are not likely to be noticed. The second problem can be anticipated if the evaluation is based on shorthand indicators and the evaluation framework is taken seriously. Service providers who are aware of the evaluation measures are likely to concentrate their efforts on those aspects which are measured to the neglect of other equally important aspects which are not measured (Campbell, 1977).

As indicated above, the distinction between opportunity and response to opportunity is important analytically. For dimensions of circumstances which involve choice, separate measurement of opportunity and actual circumstances is desirable. At a minimum, attention to the distinction adds substantially to the data to be collected. Further, measurement of opportunity is anything but straightforward. In interviewing the elderly, it has been our experience that respondents tend not to make a distinction between the following formulations:

"How often is it possible for you to . . . . .?" and

"How often do you . . . . ?"

We get more meaningful responses when opportunity questions are converted to obstacle questions, for example, "Is there anything which prevents you from seeing friends more often?" In analyzing responses to obstacles, researchers must be prepared to distinguish between environmental obstacles, such as lack of transportation, economic obstacles such as lack of money, and self-imposed obstacles such as lack of interest.

Quality of circumstances measurement presents a number of data reduction problems which remain to be resolved. One issue is the extent to which life circumstances should be considered a large number of discrete conditions or should be organized around a few summary variables. Psychometric scale analysis provides a data reduction technology which can be applied, but it is not yet clear how it will contribute or detract in the current case. One departure from conventional scale development principles has already been advocated here. Normally, items which elicit minimal response variability are excluded in scale development. It has been argued here, however, that

certain rare conditions which seriously jeopardize the functionally disabled when they occur should be included in quality of circumstances measurement.

At least in the activity domain, it has been proposed here that an adjustment should be made for functional deficits which preclude certain activities. In other words, actual activities should be interpreted within the framework of that which is physically possible. In areas in which the implications of functional deficits for activities are not entirely clear, there will be difficulties in making that adjustment.

The formulation also calls for interpretation of limited activity in the light of opportunity. Those whose limited activity in a particular dimension resulted from lack of interest on their part are considered better off than those whose limited activity is attributable to obstacles outside of their control. There is an analytic challenge, therefore, in adjusting activity reports on the basis of obstacle data.

The problem of standards deserves attention. A framework is needed for judging the adequacy of the circumstances to which home services are addressed. Standards are needed for interpretation of the data on actual circumstances. One option which should be set aside quickly is the expedient of letting individual clients establish standards for themselves. Because of variability in individual demands, a system based entirely on consumer satisfaction would invite great inequity. Further, among sophisticated consumers, such a system would encourage ever increasing service demands. Accordingly, standards must be external to recipients. They should reflect cultural expectations and be conditioned by econ[illegible] realities.

In a political or administrative context, one option is to place responsibility for standards in the hands of practitioners such as case managers. The practitioner would be given a quasi-judicial role. The advantage of this approach is that it would permit practitioners to synthesize a wide range of information, presumably in a sensible way. The disadvantage is that the practitioner might be distracted by extraneous variables such as her or his own personal values, the demands of consumers, the practitioner's personal liking or disliking of a consumer, and the limitations of agency resources.

An alternate approach would involve codification of standards. The codification in fact might be highly explicit. Conceivably, the standards might be written into legislation. More plausibly, however, legislation would authorize an administrative agency to codify, promulgate, and enforce standards. If the purpose of long term care is to enable the functionally disabled to approximate a normal life style as that is defined in this culture, it is appropriate that empirical research on cultural expectations contribute to the formulation of standards. Representatives of the general public might be surveyed about their opinions of what should be accomplished on behalf of the functionally disabled, taking into account both the desires of those affected and cost implications for the general public.

As indicated early on, family burden represents a second fundamental consumer impact domain. An important potential consequence of publicly funded home services is relief for informal providers of some of their

participation in care. One pertinent dimension of concern is strictly empirical. What is the impact of participation in long term care on informal providers? A strong argument can be made for limiting consideration to family members because it is only for them among informal caregivers that it is conceivable to think in terms of a formal expectation of participation in care. Impact on families might be felt in economic terms. Family members may contribute to in-home care by purchasing services and may also buy equipment and supplies. In addition, for informal caregivers it may be important to address lost wages which are the result of reduced participation in the labor force. It also is pertinent to look at impact in terms of consequences for the health of caregivers. Instances can be identified in which extensive participation in long term care appears to have had substantial negative consequences for the physical and mental health of caregivers. While serious negative health consequences for caregivers are clearly a concern, the question might be raised whether it should be necessary for family participants in long term care to be at serious risk of negative consequences for their own health before some relief is provided for them. Accordingly, a broader approach which addresses life style implications of participation in long term care is preferable. It might be argued that family participants in long term care themselves have a right to a normal life style. An empirical inquiry into lifestyle consequences might look at the activities of informal caregivers as they compare to persons of similar age, sex, and perhaps social class who are not involved in similar caregiving. Of pertinence might be labor force participation,

availability of free time, and discretion in use of free time. In instances in which caregivers share a household with a disabled relative, privacy for the caregiver may also be a highly pertinent dimension.

If the important dimensions of family impact can be identified, the next problem is to judge what is a reasonable level of impact on participating family members. It would be desirable if general standards might be set regarding how much family members might be expected to contribute to payment for long term care. It might be desirable to establish how much of a health risk participating family members might be asked to absorb. It might also be desirable to identify the extent to which participating family members might be expected to assume an atypical lifestyle because of their caregiving responsibilities. In this arena, the basic problems with standards are like those discussed earlier. In the abstract, one possibility is to allow each family to establish its own standards. Again, that option invites a great deal of inequity. Another option is to provide front-line workers with quasi-judicial responsibilities in applying very broad standards in individual family cases. For the same reasons discussed before, while this approach has the advantage in allowing for many idiosyncratic variables to be taken into account, it also invites a great deal of inequity. It would appear preferable to have an explicit set of standards that is applicable to all. While it is clear that such standards can be written, it is not clear that they would be fair and workable in practice. One of the complicating factors in the family arena is that there are many cases in which families with long term care participation over an extended period have redefined their lifestyles and personal expectations around their role as caregivers. We might ask to what extent that

should be expected. If standards are to be written for family participation in long term care, it would be useful if they were guided by the results of empirical research showing what general public expectations are regarding the lifestyle impact which family caregivers should be expected to absorb.

Discussion

The approach to home care objectives and evaluation presented here is simple in intent. Home care is seen as a means to enable the disabled to approximate normal lifestyles and to relieve family members who participate in care of unreasonable burdens so that they too may approximate a normal life style. The advantage of this radically social approach to objectives for long term care is that it focuses on a domain in which services can actually have a positive impact. It is an approach which can be useful in stimulating needed debate on how much should be done for the elderly disabled at public expense. The approach also provides a starting point for specifying the framework in which the contributions of various service alternatives can be evaluated.

The complexity of the quality of circumstance approach deserves comment. Evaluators understandably prefer measures which can be simply administered and scored. The quality of circumstance approach is intricate because it requires detailed data, because some of the data required are not readily obtained, because it seeks to attend to such subtle matters as the distinction between experience and opportunity, and because it calls for a framework

of standards in which to interpret empirical data. Upon first examination, the approach may be dismissed as too complex to be workable. The temptation to use short-cut approaches is certainly strong. Evaluators, for example, might try to side-step many of the issues raised here by seeking summary ratings from service recipients or relatives or even case managers through questions like these:

"All things considered, how well is _____ eating at present?"

"How well is the household maintained?"

"To what extent does _____ have the help needed to get around?"

Although a simpler approach like this certainly could be expected to elicit responses, it is deficient in its avoidance of questions regarding the information base and standards upon which judgments are made.

The home care field should not be content to settle for "quick and dirty" approaches to measurement of impact. In the years to come, enormous amounts of public funds will be spent on home care for the elderly disabled. Even though it will be expensive to develop, a well-conceived, thorough, and carefully tested method for measuring impact of home care will justify the investment by helping to provide a sound basis for public home care expenditure decisions.

The quality of circumstance approach is in the early stages of development. The set of items used in our home service study represent only one possible formulation. Our forthcoming scale analysis will certainly modify the set of items we would include in subsequent research. The standards needed as a basis for interpreting the empirical data on conditions have yet to be developed. My hope is that others will join in the effort to flesh out the approach and test its workability.

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